Arts engagement facilitated by artists with individuals with life-limiting illness

Arts engagement facilitated by artists with individuals with life-limiting illness: A systematic integrative review of the literature

Jenny Baxley Lee, MA, BC-DMT, Sonja McIlfatrick, PhD, and Lisa Fitzpatrick, PhD

Jenny Baxley Lee, MA, BC-DMT
Ulster University, Institute of Nursing and Health Sciences Research, Northern Ireland, UK
University of Florida, Center for Arts in Medicine, College of the Arts, Florida, USA

Sonja McIlfatrick, PhD
Ulster University, Institute of Nursing and Health Sciences Research, Northern Ireland, UK

Lisa Fitzpatrick, PhD
Ulster University, Arts and Humanities, Northern Ireland, UK

Correspondence concerning this article should be addressed to:
Jenny Baxley Lee, PO Box 115800, Gainesville, Florida, USA 32611-5800
Contact: jlee@arts.ufl.edu
Phone: 727-252-9902

Abstract

Background: Living with life-limiting illness significantly impacts quality of life. A growing body of evidence suggests that arts engagement facilitated by artists promotes well-being. However, no synthesis of the literature exists to describe arts engagement delivered by artists with individuals receiving palliative care.

Aim: to systematically review and synthesize evidence to identify outcomes and key knowledge gaps to inform future research and practice

Design: A systematic integrative literature review was conducted using a pre-defined search strategy and reported using PRISMA guidelines. Analysis was conducted iteratively and synthesis achieved using constant comparison to generate themes.

Data sources: PubMed/MEDLINE, CINAHL, PsycINFO, Scopus, Web of Science, and Embase were searched for studies published between database inception and August 2020. Search terms included variations on arts/artists; patients/service users; and palliative or end-of-life care. Eligibility criteria was applied and study quality assessed.

Results: Seven reviewed studies explored literary, performing, and visual arts engagement in hospitals, hospice and community settings in England, the United States, France, and Canada. Study designs, interventions and findings were discussed. Themes identified across studies associated arts engagement with 1) a sense of well-being, 2) a newly discovered, or re-framed, sense of self, 3) connection with others, and 4) challenges associated with practice.

Conclusion: Recommendations for future research were offered in order to maximize benefits, minimize risks and address complexity of artists' engagement in palliative care including: 1) consistency in methods and reporting; 2) inclusion of wider perspectives; and 3) key considerations for adapting the arts by health condition and art form.

Keywords: arts, artists, arts interventions, arts engagement, arts in health, end-of-life care, hospice, integrative review, palliative care, patients, service users

What is already known about the topic?

- An expanding body of evidence demonstrates the positive impacts of the arts on health and well-being.
- No synthesis currently exists presenting evidence on arts interventions facilitated by artists as distinct from creative arts therapists with individuals with life-limiting illness.

What this paper adds?

- This paper presents the first systematic synthesis of the benefits, challenges and key knowledge gaps in arts engagement delivered by artists in palliative and end-of-life care.
- Findings substantiate beneficial effects of the arts in palliative care, including: 1) a sense of well-being, 2) a newly discovered, or re-framed, sense of self, and 3) connection with others.
- Challenges associated with practice include navigating the complexity of facilitating arts engagement with individuals with life-limiting illness such as feelings of vulnerability, stigma, anxiety, or fatigue provoked by arts engagement.

Implications for practice, theory or policy

- Recommendations for future research include: 1) consistency in methods and reporting; 2) inclusion of wider perspectives; and 3) key considerations for adapting the arts by health condition and art form to address complexity of arts engagement in palliative care.
- This review is a step toward aggregating existing evidence to advance knowledge regarding the full potential of arts engagement and to make the arts more widely available to patients in palliative and end-of-life care.

Background

Living with life-limiting illness significantly impacts quality of life.[1-4] Life-limiting illness, defined as a condition impacting duration and quality of life, disrupts a person's sense of self [5-7] and requires coping with changes in routine and frequent healthcare visits.[8] Living with a life-limiting condition often introduces difficult-to-manage symptoms such as pain, sleep disruption, and anxiety, which contribute to reduced quality of life.[1,2,4,9] Many individuals experience social isolation following a diagnosis, which further impacts their well-being.[6,8] A goal of palliative care is to complement standard treatment with nonpharmacological modalities to manage symptoms, enhance quality of life, provide social support, and promote active living.[1-4,9]

An expanding body of evidence demonstrates positive impacts of the arts on health and well-being.[10,11] Arts on prescription, an aspect of broader social prescribing efforts, is an evidenced approach to engaging the health benefits of the arts.[12-13] Participation in music, such as singing, has been linked with positive psychoneuroimmunological effects.[10-11,13] In recent publications such as the World Health Organization's *Intersectoral Action: The Arts, Health and Well-being*[14] and the *State of the Field* reports in the United States, England, Australia, and Canada,[15-18] authors describe arts in health broadly across patient populations, however, the evidence is frequently drawn from creative arts therapies' literature, thereby missing an opportunity to articulate the role and scope of practice of artists working in healthcare settings. Distinguishing artists working in healthcare from creative arts therapists, such as a music therapist or art therapist, is useful in order to acknowledge the differences in formal education, training, and credentialing as well as the distinct aims, outcomes and strengths of engagement with each (see Table 1 for definitions of artist and creative arts therapist used for this review).

Table 1. Definitions

Definitions[35]
Artists (also known as artists in residence or artists in healthcare or health depending on context or setting) - literary, performing, visual, or multidisciplinary artists who engage in healthcare contexts such as facilitating their respective art form with a specific health population or chronic condition (i.e. dance for Parkinson's disease) ***Creative arts therapists*** (also known as music therapists, art therapists, dance/movement therapists or dance/movement psychotherapists, drama therapists) – credentialed therapists who provide creative arts therapies interventions such as music therapy, art therapy, or dance/movement therapy; often considered a health professional or mental health practitioner providing care as a healthcare team member

Documented benefits of the arts across healthcare contexts suggest potential to uniquely complement the goals of palliative care.[10,14,19-20,21-27] Fancourt and Finn's scoping review[10] identify that the arts are cost-effective, low-risk and well-positioned to address complex or difficult conditions for which there are not presently complete solutions. Studies conducted with patients in inpatient palliative care services in hospitals in the United States have suggested that engagement in the arts, including visual, performing, and literary arts activities, impacts quality of life and a sense of well-being.[19,20] Defining characteristics of palliative care[3-4,9,21-22] such as interdisciplinarity, a team approach, and life-affirming activities, offer support system, and promote living as actively as possible until death may be uniquely addressed through arts engagement. Individuals receiving palliative care, their healthcare providers, and their loved ones are invested in safe and effective care that emphasizes meaningful engagement in a patient's life beyond their illness.[5-6,28] Artists provide opportunities to engage in arts activities to achieve these goals.[5,23-29] Given the World Health Organization's (WHO) call to frame palliative care as a public health issue,[21-22] it bears consideration how artists might serve as an integral resource to palliative care teams at this time.

Illustrating a growing recognition of these practices, a 2015 *British Medical Journal* supplemental issue featured arts activities in palliative care settings with topics ranging from visual arts for legacy-making to dance in health activities for stroke patients.[30-31] Established training programs exist, such as the *Music for Healing and Transition* certification or *Mark Morris' Dance for Parkinson's Disease* program, yet no field-wide standards of practice were identified. Whilst there is growing evidence in support of arts engagement in palliative care, it remains important to describe the range and impacts of these practices.[28,32-38]

Whilst artists work in palliative and end-of-life care,[10,27-28] a limited body of evidence exists to examine and advance the full potential of arts engagement with patients, families, and clinicians. Opportunities for wider availability of the arts may be lost due to a lack of consistent use of terminology, standards of practice, formal training programs or clear professional pathways for artists.[33-38] Further, a risk of unintended harm exists without evidenced standards including agreed theoretical frames, professional competencies, and scope of practice. It is useful then to define an artist's role and to identify the skills and proficiencies that artists require when navigating palliative care.[35-38] Building an evidence base is a step toward acknowledging artists' capacity, and thereby increasing availability of the arts, in palliative or end-of-life care.[35-38]

This review aimed to systematically synthesize existing evidence and to identify outcomes such as benefits and challenges as well as key knowledge gaps in order to inform future research and practice. The review question was: "What evidence exists to describe arts engagement facilitated by artists with individuals with life-limiting illness, and what are the outcomes and key

knowledge gaps?" Literature was reviewed and findings presented as one step toward evidencing arts engagement delivered by artists working with those with life-limiting illness.

Methods

An integrative review of the literature was selected to systematically identify, appraise, and synthesise available evidence across disparate study types such as experimental and nonexperimental designs.[39-42] By engaging a pre-defined, comprehensive search strategy both rigour and a broad scope were ensured.[43-47]

Search strategy

The following databases were searched: PubMed/MEDLINE, CINAHL, PsycINFO, Scopus, Web of Science, and EMBASE. Search terms for established concepts such as *service users* or *patient* and *palliative care* or *end-of-life care* were formulated using MeSH terms, Boolean operators, and informed by key search literature. As search strategies for the arts are less formalized and well-documented, search strings for the arts and artists included variations on *visual arts, literary arts,* and *performing arts.* These terms were generated through thorough review of search literature and in discussion with experts in the field following which they were extensively tested. The term *art* was problematic in that *antiretroviral therapy* and *assistive reproductive therapies* use the abbreviation "ART" hence, synonyms were identified. Below, Table 2 exemplifies a search string.

Table 2. Search string (developed for PubMed)

Arts		Palliative Care		Patients		Exclusion Criteria
“art*” OR “arts intervention” OR "arts in medicine" OR "arts and health" OR "arts in health" OR "arts in healthcare" OR "arts for health" OR "creative arts" OR “creative expression” OR "expressive arts" OR "visual arts" OR “art making” OR art-making OR “painting" OR "drawing" OR "watercolor" OR “collage” OR "dance" OR "theat*" OR "drama" OR "music" OR "singing" OR "chor*" OR "performing art*" OR "literary art*" OR "poetry" OR "haiku" OR "oral history" OR "creative writing" OR "expressive writing" OR "storytelling" OR "mural*" OR "puppetry"	AND	"Palliative Care"[Mesh] OR "Hospice and Palliative Care Nursing"[Mesh] OR "Palliative Medicine"[Mesh] OR "Hospice Care"[Mesh] OR "Hospices"[Mesh] OR "Terminal Care"[Mesh] OR palliati*[Text Word] OR hospice[Text Word] OR "end of life"[Text Word] OR EOL[Text Word] OR dying[Text Word] OR "terminally ill"[Text Word] OR "supportive care"[Text Word]	AND	("Patients"[Mesh] OR patient[Text Word] OR patients[Text Word] OR "service users"[Text Word] OR "healthcare users"[Text Word] OR participants[Text Word] OR clients[Text Word] OR consumers[Text Word])	NOT	"art therapy"[All Fields] OR "music therapy"[All Fields] OR "dance therapy"[All Fields] OR "dance/movement therapy"[All Fields] OR "drama therapy"[All Fields] OR "psychodrama"[All Fields] OR "poetry therapy"[All Fields] OR "creative arts therapy"[All Fields] OR "creative arts therapies"[All Fields] OR "Creative Arts Therapies"[Mesh] OR "Art Therapy"[Mesh] OR "Music Therapy"[Mesh] NOT “in theat*” OR antiretroviral OR assisted reproductive therapy

Eligibility

Articles were included if they met the following criteria: 1) described a study examining literary, performing, or visual arts facilitated by an artist with individuals living with life-limiting illness and/or receiving palliative or end-of-life care; and 2) included the key terms: *palliative care, hospice, terminally ill, metastatic, or end-of-life* (see Table 3). No further restrictions were placed on study design or date of publication. The first author (J.B.L.) and a second reviewer (B.C.) independently applied the inclusion and exclusion criteria to confirm study eligibility.[46] Consensus was achieved by discussion in instances of disagreement.

Table 3. Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
○ Empirical studies including both quantitative and qualitative studies ○ Literary, performing, or visual arts interventions or engagement provided by artists with individuals living with life-limiting illness and/or interfacing with palliative or end-of-life care	○ Creative arts therapies interventions such as music therapy, art therapy, or dance/movement therapy ○ Studies with participants with a serious or chronic illness that is not life-limiting, such as stroke, cancer survivorship, dementia ○ Arts engagement provided *for or by* health professionals, trained volunteers, family members, or patients themselves

Quality appraisal

Quality appraisal was accomplished using Hawker, Payne, Kerr, Hardey, and Powell's tool[46] for the appraisal of disparate studies.[45-47] As with study eligibility, two independent reviewers (J.B.L. & B.C.) assessed the quality of each study.[46] Discrepancies in quality appraisal were discussed to achieve consensus. Hawker et al.'s tool is based on nine criteria, each ranking from one to four, such that a summed score and sub-scores could be used to grade study quality. As

with Hawker, et al's review, the purpose of critical appraisal was to allow the authors to evaluate and comment on the methodological quality of the studies. Therefore, critical appraisal of the quality and rigour outlined in the aims, methods, sampling, data analysis and results of each included paper was conducted. Critical appraisal allowed the authors to objectively and explicitly present the overall quality of the research included in this review (see Table 4) and to assess and recommend specific actions related to quality and rigour in future research such as detailed methodological reporting on the topic in the future. No studies were excluded based on their quality score.

Data extraction and synthesis

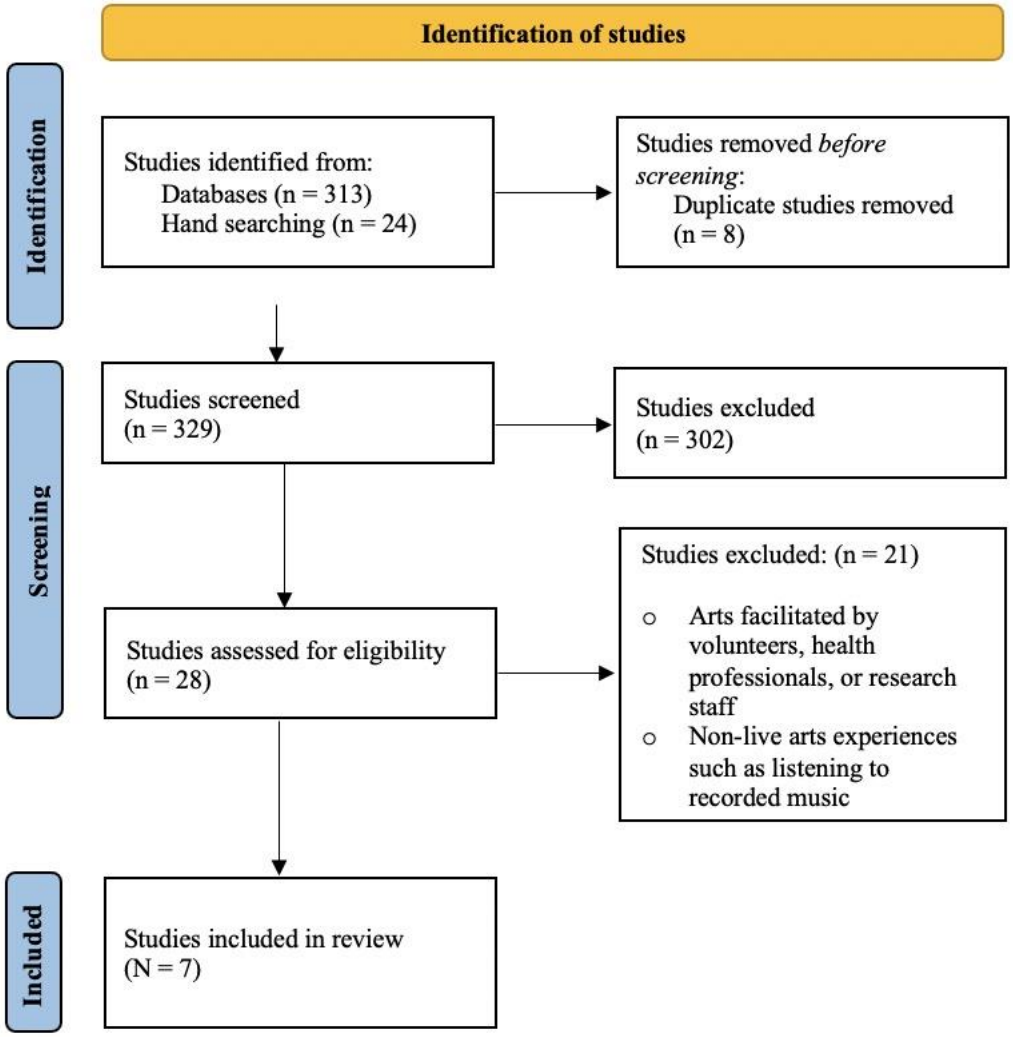
Data were extracted from each included study by the first author (J.B.L.) and an independent reviewer (B.C.) and ongoing discussion among the authors (J.B.L., S.M. & L.F.) ensured consensus was achieved. Data were organized in a matrix of study characteristics based on Whittemore and Knafl's integrative review methodology, which included: data reduction, data display, data comparison, and conclusion drawing.[41] Characteristics extracted during this step included: author, country, year of publication, design, aims, methods, participants, settings, interventions, and results (see Table 4). Analysis was then undertaken iteratively by summarizing extracted data in order to group findings and note patterns.[39-42] Prevalent patterns identified at this stage included "well-being", "newly discovered sense of self", and "connection with others" associated with arts engagement. Synthesis was achieved by further coding and categorizing data to generate themes using a constant comparison method as outlined in the data comparison and conclusion drawing steps in the integrative review framework.[41] Full articles were re-visited and a data display created in the form of a table to present relevant findings from each article in support of three overarching themes: "well-being", "sense of self" and "connection". During

synthesis, a fourth and final theme of "challenges and complexities associated with practice" was generated and was thus highlighted in Table 5.

Results

An initial database search, conducted in December of 2018, yielded 313 studies. After the database search, a hand search of journals was conducted. An additional 24 studies were identified through hand searching. Subsequently, reference lists of all articles including those of relevant review papers, were scanned. One additional article met inclusion criteria during this process and was added to the review. The search was updated in August 2020 and no additional articles were added at that time. Seven studies were eligible for inclusion in this review. Figure 1 below presents a PRISMA diagram reporting the study screening and selection process.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 flow diagram[43-45]



Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. Retrieved from: http://www.prisma-statement.org/

Overview of studies

Seven reviewed studies represented visual, literary, and performing arts engagement facilitated by artists in inpatient palliative care units in hospitals, residential and day hospice and

community settings in England, the United States, France and Canada.[19-20,48-52] Study design, interventions and findings were extracted and outlined as follows: 1) design and methods; 2) participants and settings, 3) aims and interventions, and 4) outcomes in order to summarize study characteristics and critical appraisal.[46] See Table 4.

Table 4. Study characteristics and critical appraisal[46] (*N=7)*

Author (Year) Country	**Design/ Methods/ Aims**	**Participants**	**Setting**	**Intervention**	**Results**	**Quality score** [45]
Pommeret et al. (2019) France [48]	Qualitative/semi-structured interviews **Aim:** to examine how patients hospitalized in the palliative care unit experienced a musical intervention.	Hospitalized patients receiving palliative treatment for cancer; 5 of whom were receiving end-of-life care (*n*=10)	Inpatient hospital palliative care dept.	Live music including singing and playing a musical instrument (such as guitar, piano or percussion) both 1:1 and in small groups such as with family members or staff or in the hallway Frequency, duration and intensity of live music sessions were not reported. Researcher did not provide intervention.	Positive emotions including joy and well-being Music as envelopment and immersion; a "cocoon"; humor Attention and comfort; social connection; memories Reflections on altered state of health and loss of autonomy, dying A sense of effort required and fatigue "patient as person"' "travel back and forth between the past, the present and the future."	35
Peng et al. (2018) US [19]	Mixed-methods/ Health outcomes measures including pre/post opioid use and Edmonton Symptom Assessment Scale and qualitative narrative data	Palliative care patients and their family members at time of consult (*n*=46)	Inpatient hospital	Live music to address pain, anxiety, and stress associated with end-of-life Individualized music sessions with focus on patient music selection. Frequency, duration and intensity of live music sessions were not reported. Researcher provided live flute intervention.	Significant decreases in pain, anxiety, nausea, shortness of breath, and feelings of depression Significant increase in feelings of well-being; Opioid use decreased in periods after the music intervention **Themes:** spirituality, comfort, relaxation, escape, and reflection	35

	Aim: To better understand how a live music intervention impacts palliative care patients					
Anderson et al. (2017) US [20]	Qualitative/ Thematic analysis of artist reports and patient observations **Aim:** to illustrate the artist–patient interaction and examine its contribution to interdisciplinary palliative care.	Artist reports on patient interactions in palliative care inpatient service (*n*=95)	Inpatient hospital	Music (e.g. cello, flute, violin, harp, singing), fabric art, knitting, and guided imagery Variation in frequency, duration and intensity across artists in program Researcher did not provide intervention.	1) **Patient-centered themes** relaxation, animation, spirituality, and gratitude 2) **Artist-centered themes:** professional fulfillment, kinship, and empathy with patient suffering. 3) **Patient–artist:** bonds and establishing trust. "slow time" and "slow listening"; Allows for highly personalized care	34
Sanchez-Camus (2011) England [50]	Qualitative/ Case study/ Practice article **Aim:** to explore the function of arts integration into the management of death from an arts practitioner's point of view	Hospice patients (*n*=2)	Hospice	Painting in visual arts workshops Frequency, duration and intensity not reported Author provided visual art in the case studies reported.	**Themes:** Discovery, Agency, Reassessment of their lives "enables the patient to become an active member in the management of their death process. "a collaborative endeavour" "engages patients" "a sense of control, accomplishment and appreciation" "endless possibilities to learn and explore even while dying" Rich and varied stories and memories; "Art as archive"	24
Sinding et al. (2002) CA [49]	Qualitative/ Interpretive phenomenological frame/	Women with MBC (*n*=2) Women with BC (*n*=2)	Theatre rehearsal and performance space	Theatre performance Approximately one year from collecting interviews to	Rehearsing "uncovering - making public"; making tangible	25

	research-based theatre/ interviews **Aim:** to explore interviews with women with metastatic breast cancer involved in creating a theatre performance about their experience			devising script to performance – no further detail regarding frequency of rehearsals (though 2-3 hours of a single rehearsal is noted) or frequency of performances except for mention of "multiple" It is unclear what the researcher's role was in the intervention.	Congruence – "what I say with what I viscerally know"; "Inner/outer" "Meaning of illness temporarily changed" "Moments of comfort and solace" "caring and supportive feelings [ensemble]" Asymmetry of disclosure (those with BC and those with MBC) "story hard to tell" Vulnerability: "unsupported" "unpleasant" "intensely difficult at times" Fulfilling: "I'm glad I hung in there" "virtue of hanging in, of getting and staying involved, of "acting" in relation to illness." Participatory models challenge traditional ethical frameworks; Rethink assumptions about harm Stigma of cancer: alienating, dangerous, disruptive, unmanageable Insight into patients' lived experience can educate providers	
Kennett (2000) England [51]	Qualitative/ Phenomenological/In-depth semistructured interviews and content analysis	Terminally ill patients in day hospice (*n*=10); Staff/tutors (*n*=11)	Day hospice	Visual and literary arts Weekly program of activities including pottery, painting, craft, textiles, art	**Patient themes:** • enjoyment, enthusiasm, excitement • pride accompanied by a desire to produce the best work possible; • surprise at the quality of work;	32

	Aim: to explore the experiences of terminally ill patients taking part in an exhibition of their creative arts work			therapy and creative writing groups Study covered six months of arts activities culminating in an art exhibit in which 50 patients took part The researcher did not provide the intervention.	• achievement and acquisition of new skills; • sense of purpose, incentive to achieve a goal; • competition; • valuing mutual support and sharing skills with others; • some anxiety that the work may not be good enough; • satisfaction in the permanence of the work; • hope. A subgroup of above-identified themes: expressions of self-esteem, autonomy, social integration, and hope Anticlimax when the exhibit was over	
McLoughlin(2000) England [52]	Qualitative/ Practice article **Aim:** to explore a creative writing project undertaken with patients in a hospice day centre	Patients in day hospice (*n*=NA)	Day hospice	Creative writing in small group One session per week; 90 minutes; open enrollment such that members could freely join or exit The author provided the intervention.	Writing group provides time out from illness; enjoyment in literature; patients as individuals; Group provides a place to reduce isolation and spontaneity, surprise, play, control, reverie and concentration Consistency is key Expressed emotion over time	20

Design and methods

Design, methods, and quality varied among studies with a prevalence of qualitative methods (*n=7*): semi-structured interviews in three studies, [48,49,51] one analysis of artists' documentation and patient observations, [20] and one descriptive practice article featuring a set of case studies.[50] One mixed methods study collected the Edmonton Symptom Assessment Scale and opioid usage

before and after live music as well as stories and quotes of patients and family members' experiences.[19] It was also noted that in three studies, the researcher participated in the intervention[19, 50, 52], and in three studies, they did not[20,48,51]. In one study, researchers' role in the intervention was unclear[49].

Participants and settings

Studies were conducted in England (*n*=3),[50-52] the United States (*n*=2),[19-20] France (*n*=1), [48] and Canada (*n*=1).[49] Study participants (*N*=178) included individuals with life-limiting illness (*n*=72), artists or staff/tutors (*n*=106), and family members (*n*=NA). Two studies included a small percentage of overall participants for whom illness was not life-limiting, for example, non-metastatic breast cancer (*n*=7).[48,49] One study included family members but did not specify how many participated[19]. Several studies (*n*=3) included adults receiving inpatient palliative care in hospitals: one included patient observation of sessions with adult cancer patients (*n*=95),[20] a second included semi-structured interviews with palliative care patients (*n*=10),[48] and a third focused on patients and their family members (*n*=46).[19]

In the only case study reviewed, participants were adult patients in residential hospice (*n*=2).[50] Of the two studies with patients in day hospice,[51,52] only one reported the number of participants (*n* = 10).[51] In addition to patient self-report, two studies introduced perspectives other than patients.[20,51] These included artists' documentation of their interactions with palliative care patients[20] and artists' description of facilitating group process such as how much they chose to direct the participants' art making versus allowing broader freedom of expression.[51]

Aims and interventions

Frequency, duration and intensity of arts interventions varied across studies. Study aims commonly sought to explore or describe arts engagement primarily described as “experiences”, “interactions, “projects”, “exhibition” and “performance” with individuals living with life-limiting illness. Notably, the term “intervention” was only utilized in two recent studies.[19,48]

Creative writing and the literary arts represented four of seven studies.[20,49,51,52] Live music played for patients who participated through song selection was an intervention in two studies and one of several arts modalities in a third study.[19,20,48] Three studies included visual arts activities such as painting, mixed media, pottery, sculpture, knitting, and textile arts.[20,50,51] Only one study featured playwriting and theatre performance.[49] Dance and movement were mentioned in a study of a multidisciplinary program designed to “integrate the arts as standard of care” by offering live music and movement alongside visual and literary arts.[20] In three studies, arts engagement took place one-to-one or in small groups centered on patients and any visitors who were present.[19-20,48] In three studies, arts engagement occurred in small groups of patients, referenced as a workshop.[49-52]

Themes

Primary themes generated from analysis and synthesis of study findings included: 1) a sense of well-being;[19-20,48,50-52] 2) a newly discovered – or re-framed – sense of self;[20,48-51] and 3) connection with others.[20,49-52] These three themes were generated from patient self-report or artists or staff observation of arts engagement with patients. A fourth theme of challenges reported across studies was of vital consideration.[20,48,49,51] This theme was generated from the perspectives of researchers who either facilitated arts engagement directly or who included artists’ perspectives as data.

Well-being

The theme of a *sense of well-being* was identified in six studies.[19-20,48,50-52] Terms such as "enjoyment," "invigoration," or "enthusiasm" exemplified this theme. Meaning-making and spirituality, aspects contributing to well-being, were noted as themes in three studies.[19-20,50] Peng and colleagues reported "spirituality, comfort, relaxation, escape, and reflection."[19] Anderson and colleagues reported that patients experienced "relaxation, gratitude, invigoration, and accessing spirituality" associated with art-making. Patient self-report confirmed these observations.[20] Pommeret et al.'s study contributed a balance of weighing patients' positive emotions such as "joy and well-being" with challenges described as "fatigue", "effort", and reflection on dying or on how illness has altered their lives and sense of autonomy.[48] Challenges are explored in further detail below.

Peng et al. was the only study that featured quantitative findings by reporting on the Edmonton Symptom Assessment Scale (ESAS) and the measurement of opioid usage before and after the intervention.[19] Following a live music intervention, patients reported decreases in symptoms such as pain, nausea, shortness of breath, anxiety, and feelings of depression. The authors also documented a decrease in opioid usage and an increase in a reported sense of well-being.

Discovering, or re-framing, sense of self

A second theme was a newly discovered sense of one's self as evidenced by findings such as "discovery," "agency," or "self-esteem" through "reflection", "expression", and "archiving stories and memories".[20,48-51] This theme was identified in six studies included in this review.

Sánchez-Camus' case studies reported themes such as patients' "sense of discovery", "agency", and "accomplishment".[50] This study highlighted the unique ability of the arts to create an opportunity for reflection and meaning-making and to archive stories and memories for patients and their loved ones. One study observed how live music transforms its audience members "from patient to person".[48] McLoughlin noted value in a "time out from illness" pointing to an ability of the arts to re-frame a patient's identity beyond illness.[52]

Connection

The theme of connection, identified explicitly in six studies, was identified through terms such as "collaborative endeavours", "mutual support", and "social connection".[20,49-52] Anderson and co-authors described "establishing trust and bonds" between artists and patients.[20] Artists in this study reported a sense of "professional fulfillment", "kinship", and contributions to "highly personalized care" through enhanced communication with family and staff correlated with arts engagement. McLoughlin reported that patients experienced "enjoyment and connection" through reading literature and writing.[52] This study reported that the consistency and reliability of the facilitator and group members were key to participants' opening up to one another and expressing emotion in the group.

Challenges

Authors in four of the reviewed studies highlighted challenges and complexity in designing and delivering arts interventions[20,48,49,51] such as navigating feelings of vulnerability, stigma, anxiety, or fatigue provoked by arts engagement. Sinding and colleagues described exploring the effects of playwriting and a theatre performance with two women with metastatic breast cancer

and two women with nonmetastatic breast cancer.[49] Whilst many themes reinforced the findings of the other articles, such as meaning-making, connection, and "moments of comfort", the authors also reported an asymmetry in experiences between actors living with metastatic breast cancer and those who were not. The purpose of the study was to "create a drama, working from a focus group study and series of interviews with oncologists conducted the previous year about the information needs of women with metastatic breast cancer" and "to explore what it means to have metastatic disease and to provide oncological care to [these] women". This study reported that feelings of vulnerability, stigma, and the alienation of living with life-limiting illness were activated by the intervention. Pommeret and colleagues reported similar findings with live music played for patients in both 1:1 and small-group settings as music, which introduced a "pause" in care and, therefore, time for patients to reflect.[48] Whilst the study reported a wide range of positive aspects aligning with the thematic findings of a sense of well-being and social connection, the authors also noted limitations and challenges "hesitation", "anxiety", "effort", and "fatigue" on the part of the patients. Practitioner difficulties also arose including song choice.

The arts interventions in Sinding et al.[49] and Kennett[51] both included public-facing artwork through a theatre performance and visual art exhibit, respectively. Sinding and colleagues described the experience of rehearsing as invaluable to women living with breast cancer and asserted that whilst "participatory models challenge traditional ethical frameworks," they present an opportunity to "rethink assumptions about harm" in research. Kennett reported that participants described feelings of well-being overall that are consistent with the themes mentioned above, such as "excitement", "pride", "purpose", "agency", and "connection". The

public-facing aspect of the work in Kennett's study, however, introduced anxiety-producing elements of art making, a sense of competition between group members, and anticlimax when the exhibit was over. Participants also reported finding value in making something tangible and permanent, having an incentive to reach a goal, and a sense of satisfaction at having produced a high quality of work.

Abovementioned study characteristics were analyzed to reveal key findings and study limitations to explore broader implications of the review, which will now be discussed.

Table 5. Key findings and study limitations (*N*=7)

Author (Year) Country	**Key findings**	**Limitations**
Pommeret et al., 2019, France	Singing and playing a musical instrument brought joy and well-being to patients and to the palliative care unit. Patients encountered difficulties during intervention: reference to an altered general state, to loss of autonomy; a sense of effort required, of fatigue; an adaptation period; reference to end-of-life, to death; a difficulty in choosing songs.	Small number of participants Investigator was the unit psychologist, potentially increasing "desirability bias"
Peng et al., 2019 United States	Music as non-pharmacological symptom management in palliative care Decrease in opioid use Decrease in reported pain, anxiety, nausea, shortness of breath, feelings of depression Significant increase in wellbeing	Lead author served in dual capacities as researcher/ author and flute player in intervention Small cohort due to low patient census No control group Challenges isolating variables, for example, benefits of live music versus the presence of a musician
	Themes: spirituality, comfort, relaxation, escape, and reflection	

Anderson et al. (2017) United States [20]	Patient themes: Artists observed physical, emotional, and spiritual responses in patients including relaxation, invigoration, and accessing spirituality, unique to artist-patient interaction. Artist themes: professional fulfillment, kinship, and empathy with patient suffering. Artist-patient bond and trust with patients	Patient observations by artists who facilitate the interaction observed may present bias Difficult to compare across artistic disciplines No patient or health professional perspectives
Sanchez-Camus (2011) England [50]	Themes: Creative process assists dying person in dealing with complexities of transitional phase Art-making allows objectivity and critical thinking, placemaking through memory, legacy, new narration of life when faced with death	Two case studies in different contexts Highly conceptual and lacking concrete detail about intensity, duration or frequency of practice/intervention
Sinding et al. (2002) CA [49]	Theatre as rehearsing behavior Making tangible Congruence of inner and outer – "what I say with what I viscerally know" Meaning-making Moments of comfort and solace Social cohesion: "caring and supportive feelings from [ensemble]" I'm glad I hung in there" – "fulfilling" Rethink assumptions about harm Insight into patients' lived experience educates providers	Painful disclosure Vulnerability Precarious position of the understudy – "unsupported" and "unpleasant" "intensely difficult at times" Participatory models challenge traditional ethical frameworks Stigma is alienating
Kennett (2000) England [51]	Raw Themes: enjoyment, enthusiasm, excitement, pride, achievement, satisfaction, sense of purpose, mutual support, permanence (legacy) Distilled Themes: positive expressions of self-esteem, autonomy, social integration, and hope.	Small sample A wide range of disciplines represented but not clearly linked to specific themes or findings Art therapy included among art activities in the study, though clearly distinguished

	Hope as the essence of the phenomenon, important in palliative care where continuation of active medical intervention has been equated with the provision of hope.	
McLoughlin (2000) England [52]	Benefits of poetry include: enjoyment, sustenance, therapeutic (contains anxiety), inspirational, giving form/containing, joy, comfort, welcoming, self-exploration, spontaneity, play, surprise, control, reverie, and concentration Transition and transitional space is common to hospice and poetry both Poetry helps patients negotiate changes brought about by illness Prizes patients as individuals and reduces isolation	Author/researcher facilitated poetry/creative writing intervention Lacking a clear study aim and rigour as design, method and analysis not discussed

Discussion

Findings of this review suggested that arts engagement can elicit an individualized, substantive, and positive experience amongst individuals living with life-limiting illness. Findings also suggested that challenges arise in practice worth examining further. Primary themes reported in these studies built upon existing evidence in the field of arts in health.[10-18] It was well documented in arts in health literature that arts engagement promotes meaning-making, discovery, reflection, and expression yielding a sense of well-being, self-discovery, and connection with others. This knowledge was reinforced by the studies on the arts in palliative care included in this review.[10,14-18] Arts engagement offered opportunities for patients to examine and embody the question "what gives your life meaning?", thereby enhancing well-being and connection among patients, family members and care providers.[23-26] While it can be argued that an evidence base is emerging to underpin arts engagement toward the primary aims

of palliative care, a lack of quality and rigour as well as a small number of total studies highlighted the need for formal research on the review topic.

Of the seven studies reviewed, participants were predominantly adult patients, though staff and artists were included in two studies each.[19,51] Creative writing was the most prevalent discipline represented, followed by visual arts and music. Dance, playwriting, and theatre performance were underrepresented, included in only one study each.[49] No studies included pediatric patients. Herein, some specific challenges and opportunities inherent to the findings emerged.

Specific challenges and opportunities

Findings of the reviewed studies highlighted challenges and opportunities in facilitating the arts in palliative care. Impacts bearing further examination included: 1) a role for the arts in symptom management, 2) navigating unique contexts such as one-to-one bedside practice in hospital settings or public-facing, patient-created art works, and 3) collaborating with clinicians to enhance arts engagement. In order to safely and effectively navigate alongside patients who are experiencing difficult-to-manage physical symptoms and social isolation, as introduced in these studies, artists benefit from working knowledge of adapting arts engagement for healthcare contexts.[45,48,49,53]

Arts engagement and symptom management

In the only mixed methods study included,[19] arts engagement was incorporated into palliative care as a means of nonpharmacological symptom management. Researchers reported significant physiological impacts of live music such as decreases in pain, anxiety, nausea, shortness of breath, and feelings of depression along with a significant increase in feelings of well-being.

Investigators also noted that opioid use decreased in experimental participants in the period following music as compared to the control among participants who did not elect to participate in music. A mixed methods approach bears further exploration, given the emphasis in palliative care on providing nonpharmacological treatments for symptom management.[1-9] This same study introduced that it was a challenge to isolate variables, for example, determining the benefits of live music versus the presence of a musician, which presents further rationale for mixed methods approaches.

Adapting arts engagement to clinical or community contexts

Sinding and co-authors' description of creating a theatre performance with women with breast cancer[49] alongside Kennett's description of a collaborative art exhibition[51] revealed that specific considerations are critical to implementing public-facing work in safe and effective ways. These programs may also offer unique benefits when implemented within scope. Pommeret and colleagues presented patient- and practice-related difficulties[48] encountered in hospital settings during and following live music with patients. Fatigue, loss of autonomy, and references to death or dying all must be navigated and the arts adapted to meet the unique needs of patients receiving palliative or end-of-life care. Studies included in this review identified professional practice-related challenges such as song selection that bear exploring further. These findings presented a critical opportunity to shape future research to inform practice.

Arts engagement in collaboration with palliative care teams

In keeping with the ethos of palliative care, several studies highlighted the value of artist collaboration with clinicians on the healthcare team.[19,20,48,51] Clinician interactions with artists included referring patients to an arts program, informing artists' of relevant patient health status, and assisting patients with coming and going from an arts workshop. Further, these observations

raised the question of how the arts could become more integrated into the delivery of palliative care services, perhaps in a manner that improves quality of care and provides respite and support for the team.[53] In framing palliative care in a public health context, further discussion is warranted as to how the expertise of artists working in public health might be engaged in collaboration with palliative care teams.[21-22]

Recommendations for future research

Based on the present review, the following four recommendations are made to further understand how to maximize benefits and address challenges inherent to practice. Recommendations include: 1) consistency, specificity and transparency in methods and reporting; 2) mixed methods and multi-center research efforts; 3) wider range of perspectives; and 4) considerations by context, population and art form.

Recommendation 1: Consistency, specificity and transparency in methods and reporting

Reporting

The present review reveals challenges in consistency of methods and reporting among extant studies on arts engagement in palliative and end-of-life care. Consistency in reporting advances reproducibility and generalizability allowing for a more robust synthesis of findings. Future studies would therefore benefit from consistency in frequency, duration and intensity of the intervention, as indicated in a study on complementary interventions in palliative care conducted by Armstrong and colleagues.[54] Reporting should include transparency and specificity regarding the intervention including theoretical or conceptual frameworks, role descriptions, and training and orientation to palliative or end-of-life care contexts.

Replicability will be enhanced through consistent use of validated scales such as those measuring well-being or quality of life. The Edmonton Symptom Assessment Scale was included in one study in this review, however the Warwick-Edinburgh Mental Well-being Scale, the General Self-Efficacy Scale, or the Health-Related Quality of Life are also frequently used in arts in health research.[10,13,29]

Methods

Mixed methods study designs address the interdisciplinarity and complexity of the study topic by integrating health sciences' and social sciences' approaches.[55] Mixed methods studies allow for the convergence and integration of qualitative and quantitative findings, and when conducted with quality and rigour, may contribute to transferability and/or generalizability of findings.[55-56] Multi-center research efforts may also serve to enhance success with recruitment and enrollment, for example, where small cohorts limit generalizability. In these ways, research efforts may meaningfully advance understanding of delivery of the arts by artists with patients in palliative care.

Recommendation 2: Exploring a wider range of perspectives

Notably, the findings center patients' perceptions, which demonstrates perceived value in arts engagement to complement the social and existential aims of palliative care. It would be constructive to consider family members and clinicians' perspectives, as they are included in only one study.[19] Whilst clinicians focus broadly on physical care and comfort, the arts amplify holistic aspects of care and therefore, align with and fulfill the broader aims of palliative care.

Whilst the goal of the present review was to maintain a narrow focus on artists' delivery of the arts with individuals with life-limiting illness, it bears consideration that a range of clinicians have expertise and investment in arts engagement as clinical care. For example, arts engagement with pediatric palliative care patients benefits from collaboration with Child Life specialists or creative arts therapists.[4,26] Another study introduced an arts program in hospice featuring artists and creative arts therapists working cooperatively. An interdisciplinary and collaborative model such as this is worth exploring further.[57]

Studies exploring arts engagement delivered by allied health professionals, the use of the arts in nursing or medical education or to enhance the clinical environment are each worth examining in their own right. Examples include the work of chaplains or occupational therapists with patients in palliative care settings.[58-63] Creative activities such as "legacy projects", "life reviews", and "illness narratives" notably share some common elements with the review topic. The arts complement occupational therapy aims like "creative occupation" or a chaplaincy aim of "meaning construction'.[59,62-64] Studies examining the role of the arts to enhance nursing or medical education,[64-65] to prevent health care provider burnout,[66-67] or to enhance the healthcare environment[68] bear future exploration in an effort to map the extent of the range and reach of the arts in palliative care.

Recommendation 3: Considerations for adapting delivery of the arts by context, health condition and/or art form

Additional consideration is recommended in adapting delivery of the arts by context, setting, health condition or art form to address unique concerns or developmental needs. By excluding

clusters of conditions such as dementia, studies describing artists' work in dementia care were not outlined.[69] Due to the nuances of dementia care, the authors recommend that this area is explored independently to account for a large body of literature and practical considerations specific to changes in cognitive functioning.[70-72] Similarly, dance programs for Parkinson's disease offer a model of standardized practice, which is well-structured and mapped in the literature.[72-76] These are examples of what is possible when research efforts are coordinated.

In three studies not included in the present review, researchers engaged expressive writing with women with metastatic breast cancer.[77-79] These studies introduced feasibility issues with intervention delivery, adherence, and follow up. Ease of recruitment indicated patient interest in an arts-based intervention, adherence was low[77] and patients reported distress immediately following the intervention. In one instance, an increase in the use of mental health services following the intervention is documented.[78] Reported feasibility issues may demonstrate the value of an artists' expertise in facilitation. Therefore, it is recommended that a research agenda is mapped to assess risks in order to anticipate and address issues with interventions or measures.

Finally, artists are rapidly adapting the arts through remote delivery and this work may have significant implications for palliative and end-of-life care. Given the impacts of the current pandemic, the implications of social isolation whilst living with a life-limiting illness are even more pronounced than in the past.[80-82] The pandemic has introduced a new and collective layer of stress and a role for artists who can adeptly facilitate virtual arts engagement bears consideration[83-84]. These recommendations are outlined in Table 6.

Table 6. Recommendations for future research

Recommendations for future research to inform practice and policy

Recommendation 1: *Consistency, specificity and transparency in methods and reporting*
Reporting
1. Consistent reporting guidelines to include:
  o duration, frequency, and intensity of intervention;
  o theoretical or conceptual frames of practice;
2. Consistent use of search terms
3. Consistent outcomes measures
Methods
1. Mixed-methods designs and multi-center studies
2. Overall quality and rigour to increase generalizability and/or transferability
3. Enhance recruitment and enrollment

Recommendation 3: *Explore a wider range of perspectives* 1. Artists, clinicians, program coordinators, and family members' perspectives 2. Interprofessional collaborations between artists and palliative care teams 3. Wider demographic representation in studies considering key variables such as age, race, gender, geographical location
Recommendation 3: *Considerations for adapting delivery of the arts* 1. Discipline-specific studies such as music, drama, dance, poetry, creative writing, or visual art such as live music in Peng, et al and Pommeret, et al.[19,48] 2. Population-, condition-, setting- and/or developmentally-specific studies such as an arts workshop for those living with an advanced-stage cancer diagnosis, pediatric studies, or setting-specific studies such as residential hospice 3. Nuances of arts engagement parsed out by health condition with consideration for specialized needs, common symptoms and experiences, environment of care, and palliative care team, as appropriate. 4. Artists' expertise working in public health contexts and who are facilitating virtual arts engagement based in part on innovations in response to the pandemic

Strengths

A strength of this review is its integrative design, which allowed for a thorough and systematic search through a broad body of literature, including experimental and nonexperimental studies to synthesize a wide array of evidence. Another strength is the wide range of perspectives through

which the arts are considered including patients, artists, and to a limited extent, family members and staff. This allows for multiple views of practice to emerge. Several studies also had similar characteristics allowing for meaningful comparisons to be drawn. As well-designed studies with fastidious and consistent reporting of protocols and interventions are added to the literature, additional such comparisons across studies may advance evidence-based practice to meet the unique needs of patients in palliative care. Steps can then be taken at a policy-level to adopt and implement these standards to benefit patients, artists, and the healthcare organizations within which they serve.

Limitations

One limitation was the small body of literature identified by the search. Additional study limitations include disparate and heterogeneous designs, methodologies and participants, although this could be framed as a strength should a larger body of literature on the subject exist. Frequency, duration and intensity of interventions were unreported in three studies[19,48,50] and underreported in four studies.[20,49,51,52] Five studies had small cohorts of two to ten participants thereby limiting the ability to generalize findings.[48-52] Two studies included multiple art forms such as music, art, and poetry in multiple settings ranging from hospitals to hospice to community settings and home environments.[20,51]

As just seven studies were identified, there is a lack of geographical representation and diversity of study participants including key variables such as age, race, or gender thereby impacting generalizability. A key component of this review was to focus on artists to the exclusion of creative arts therapists. Whilst the study aimed to describe artists' work thereby gleaning insight

from a gap in the literature, creative arts therapies' literature notably overlaps with the review topic.

Conclusion

This integrative review synthesizes evidence and identifies knowledge gaps in arts engagement by artists in palliative and end-of-life care. Given that individuals living with life-limiting illness with limited treatment options benefit from a range of non-pharmacological measures to manage symptoms and enhance quality of life, this study points to positive associations between arts engagement and a sense of well-being, a sense of self, and connection with others. Findings moderately substantiate benefits, illuminate complexities, and introduce knowledge gaps regarding arts engagement by artists with patients receiving palliative and end-of-life care, therein substantiating a need for further research to guide policy and practice. As stated above, recommendations for future research are made to further understand how to maximize benefits, minimize risks and address challenges of these practices, such as 1) consistency, specificity and transparency in methods and reporting; 2) wider range of perspectives; and 3) adaptations of arts engagement by context, population and art form.

Whilst there are significant developments in professionalizing arts engagement in palliative and/or end-of-life care, a gap remains hence synthesis of the evidence is positioned for wider impact. Given what is known about the vulnerability of individuals living with life-limiting illness, amplified during a time of pandemic, and the value of safe, effective, and meaningful arts engagement, it is critical to systematically examine available evidence. This review is one step toward aggregating existing evidence to further efforts to make the arts more widely available to individuals living with life-limiting illness.

Declarations

- Ethics approval and consent to participate
- Consent for publication
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Competing interests

The authors, J.B.L, S.M., and L.F., declare that they have no competing interests with respect to the research or authorship.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Authors' contributions

All authors, J.B.L, S.M., and L.F. made substantial intellectual contributions from conception and design through to the manuscript at each step of development. J.B.L. conducted the searches, primary and secondary screening, critical appraisal, data extraction and analysis, and manuscript preparation. S.M. and L.F. contributed to conception and design as well as intellectual

contribution within each section of the manuscript, and critical appraisal of the manuscript. All authors have critically revised and given the final approval of the manuscript to be submitted for publication.

Acknowledgments

The authors wish to thank Brittni Cleland for research and technical assistance, Maggie Ansell in the University of Florida Health Sciences Libraries for assistance with the development and testing of a search strategy, and Jill Sonke and the members of the Center for Arts in Medicine research lab for input during the development of the review such as identifying search terms.

Availability of data and materials

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Supplemental material

Any supplemental material for this article is available online.

References

1. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative care: the World Health Organization's global perspective. Journal of pain and symptom management 2002; 24(2):91-6.
2. Knaul FM, Bhadelia A, Rodriguez NM, Arreola-Ornelas H, Zimmermann C. The Lancet Commission on palliative care and pain relief—findings, recommendations, and future directions. Lancet Global Health 2018; 6:S5-6.
3. Meier DE, Brawley OW. Palliative care and the quality of life. Journal of clinical oncology 2011; 29(20):27-50.
4. Long CO. Cultural and spiritual considerations in palliative care. Journal of pediatric hematology/oncology 2011; 33:S96-101.
5. Romanoff BD, Thompson BE. Meaning construction in palliative care: The use of narrative, ritual, and the expressive arts. American Journal of Hospice and Palliative Medicine® 2006; 23(4):309-16.
6. Charmaz K. Measuring pursuits, marking self: Meaning construction in chronic illness. Int J of qualitative studies on health and well-being 2006; 1(1):27-37.

7. Greer JA, Applebaum AJ, Jacobsen JC, Temel JS, Jackson VA. Understanding and addressing the role of coping in palliative care for patients with advanced cancer. Journal of clinical oncology 2020; 38(9):915-25.
8. Henson LA, Maddocks M, Evans C, Davidson M, Hicks S, Higginson IJ. Palliative care and the management of common distressing symptoms in advanced cancer: Pain, breathlessness, nausea and vomiting, and fatigue. Journal of clinical oncology 2020; Mar 20;38(9):905.
9. World Health Organization. What is palliative care. 2018.
10. Fancourt D, Finn S. What is the evidence on the role of the arts in improving health and well-being? A scoping review, WHO Regional Office for Europe, Copenhagen, 2019.
11. Fancourt D, Ockelford A, Belai A. The psychoneuroimmunological effects of music: A systematic review and a new model. Brain, behavior, and immunity 2014; 36:15-26.
12. Bungay H, Clift S. Arts on prescription: a review of practice in the UK. Perspectives in public health. 2010; 130(6):277-81.
13. Fancourt D, Warran K, Finn S, Wiseman T. Psychosocial singing interventions for the mental health and well-being of family carers of patients with cancer: results from a longitudinal controlled study. BMJ open 2019; 9(8):e026995.
14. World Health Organization. Intersectoral action: the arts, health, and wellbeing. 2019. Government brief. WHO website.
15. Wreford G. The state of arts and health in Australia. Arts & Health 2010; 2(1):8-22.
16. Clift S, M. Camic P, Chapman B, Clayton G, Daykin N, Eades G, Parkinson C, Secker J, Stickley T, White M. The state of arts and health in England. Int Journal of Arts and Health 2009; 1(1):6-35.
17. Cox SM, Lafrenière D, Brett-MacLean P, Collie K, Cooley N, Dunbrack J, Frager G. Tipping the iceberg? The state of arts and health in Canada. Int Journal of Arts and Health 2010; 2(2):109-24.
18. Sonke J, Rollins J, Brandman R, Graham-Pole J. The state of the arts in healthcare in the United States. Int Journal of Arts and Health 2009; 1(2):107-35.
19. Peng CS, Baxter K, Lally KM. Music intervention as a tool in improving patient experience in palliative care. Amer J of hospice and palliative medicine 2019; 36(1):45-9.
20. Anderson KG, Langley J, O'Brien K, Paul S, Graves K. Examining the artist–patient relationship in palliative care. A thematic analysis of artist reflections on encounters with palliative patients. Int Journal of Arts and Health 2019; 11(1):67-78.
21. Callaway MV, Connor SR, Foley KM. World Health Organization public health model: a roadmap for palliative care development. Journal of pain and symptom management 2018; 55(2):S6-13.
22. World Health Organization. Strengthening of palliative care as a component of integrated treatment throughout the life course. Int J of pain and palliative care pharmacotherapy 2014; 28(2):130-4.
23. Hartley N. End of Life Care: A guide for therapists, artists and arts therapists. Jessica Kingsley Publishers; 2013.
24. Butchers A, Dobbs S, Sands M, Tasker M, Hearth V, Harmer L, Gill A. The creative arts in palliative care. Jessica Kingsley Publishers; 2008.
25. Jarrett L, editor. Creative engagement in palliative care: New perspectives on user involvement. Radcliffe Publishing; 2007.
26. Rollins JA, Riccio LL. Art is the heart: A palette of possibilities for hospice care. Pediatric nursing 2002; 28(4):355-62.

27. Carswell C, Reid J, Walsh I, Johnston W, McAneney H, Mullan R, Lee JB, Nelson H, Matthews M, Weatherup E, Spencer A. A mixed methods feasibility study of an arts-based intervention for patients receiving maintenance haemodialysis. BMC nephrology 2020; 21(1):1-6.
28. Carswell C, Reid J, Walsh I, McAneney H, Lee JB, Noble H. Complex arts-based interventions for patients receiving haemodialysis: A realist review. Int Journal of Arts and Health 2020; 1-27.
29. Fancourt D, Williamon A, Carvalho LA, Steptoe A, Dow R, Lewis I. Singing modulates mood, stress, cortisol, cytokine and neuropeptide activity in cancer patients and carers. Ecancermedicalscience 2016; 10.
30. Pearson J, Stansfield K. P-1 Arts and palliative care at the prince and princess of wales hospice 2015; 5(Suppl 3). BMJ supportive and palliative care.
31. Haraldsdottir E, Christie L, McArthur J. P-12 Art and hospice care-building a strategic relationship. BMJ supportive and palliative care 2015; 5(Suppl 3).
32. Dileo C, Bradt J. On creating the discipline, profession, and evidence in the field of arts and healthcare. Int Journal of Arts and Health 2009; 1(2):168-82.
33. Broderick S. Arts practices in unreasonable doubt? Reflections on understandings of arts practices in healthcare contexts. Int Journal of Arts and Health 2011; 3(2):95-109.
34. Raw A, Lewis S, Russell A, Macnaughton J. A hole in the heart: Confronting the drive for evidence-based impact research in arts and health. Int Journal of Arts and Health 2012; 4(2):97-108.
35. Moss H, O'Neill D. What training do artists need to work in healthcare settings?. Medical humanities 2009; 35(2):101-5.
36. Sonke J. Professionalizing the arts in healthcare field. In Managing arts programs in healthcare 2015; (pp. 50-62). Routledge.
37. White M. Developing guidelines for good practice in participatory arts-in-health-care contexts. Journal of Applied Arts & Health. 2010 Jul 1;1(2):139-55.
38. Hastwell R. Strengthening the links between arts, education and health promotion: A case for building the capacity of artists to work across sectors. International Journal of the Arts in Society. 2012 Oct ;6(5).
39. Whittemore R, Knafl K. The integrative review: updated methodology. Journal of advanced nursing 2005;52(5):546-53.
40. Whittemore R. Combining evidence in nursing research: methods and implications. Nursing research 2005; 54(1):56-62.
41. Whittemore R. Rigour in integrative reviews. Reviewing research evidence for nursing practice: Systematic reviews 2007; 149-56.
42. Cooper HM. Scientific guidelines for conducting integrative research reviews. Review of educational research 1982; 52(2):291-302.
43. Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart LA. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. Systematic reviews 2015; 4(1):1.
44. Moher D, Liberati A, Tetzlaff J, Altman DG, Prisma Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS med 2009; 6(7):e1000097.

45. Page MJ, Moher D, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R. PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. bmj. 2021 Mar 29;372.
46. Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: reviewing disparate data systematically. Qualitative health research 2002; 12(9):1284-99.
47. Pluye P, Gagnon MP, Griffiths F, Johnson-Lafleur J. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. Int J Nurs Stud 2009; 46(4):529-46.
48. Pommeret S, Chrusciel J, Verlaine C, Filbet M, Tricou C, Sanchez S, Hannetel L. Music in palliative care: a qualitative study with patients suffering from cancer. BMC palliative care 2019; 18(1):1-6.
49. Sinding C, Gray R, Fitch M, Greenberg M. Staging breast cancer, rehearsing metastatic disease. Qualitative health research 2002; 12(1):61-73.
50. Sánchez-Camus R. The art of dying: Aesthetics and palliative care. Journal of applied arts & health 201; 2(2):155-6
51. Kennett CE. Participation in a creative arts project can foster hope in a hospice day centre. Palliative medicine 2000; 14(5):419-25.
52. McLoughlin D. Transition, transformation and the art of losing: Some uses of poetry in hospice care for the terminally ill. Psychodynamic counselling 2000; 6(2):215-34.
53. Sonke J, Pesata V, Lee JB, Graham-Pole J. Nurse perceptions of artists as collaborators in interprofessional care teams. Healthcare 2017; 5(3): 50.
54. Armstrong M, Kupeli N, Flemming K, Stone P, Wilkinson S, Candy B. Complementary therapy in palliative care: A synthesis of qualitative and quantitative systematic reviews. Palliative medicine. 2020 Dec;34(10):1332-9.
55. Vedel I, Kaur, N, Hong QN, El Sherif R, Khanassov V, Godard-Sebillotte C, Sourial N, Yang XQ, Pluye P. Why and how to use mixed methods in primary health care research. Family practice 2019 Jun;36(3):365-8.
56. Watkins D, Gioia D. Mixed methods research. Oxford University Press; 2015.
57. Gallagher A. A pilot evaluation of the Arts for Life project in EOL care. Nursing Standard 2008; 22(50):42-7.
58. Collins A, Ayre S, Brulotte T, Crowe K, Nekolaichuk C. A retrospective thematic analysis of patient, family, and staff creative art tiles developed on a tertiary palliative care unit. American Journal of Hospice and Palliative Medicine®. 2020 Jun 29:1049909120935833.
59. Collins A. "It's very humbling": The effect experienced by those who facilitate a legacy project session within palliative care. American Journal of Hospice and Palliative Medicine®. 2019 Jan;36(1):65-71.
60. O'Callaghan, C., Byrne, L., Cokalis, E., Glenister, D., Santilli, M., Clark, R., … Michael, N. "Life within the person comes to the fore": Pastoral workers' practice wisdom on using arts in palliative care. The American Journal of Hospice & Palliative Care 2018; 35(7), 1000–1008.
61. Tees, B., & Budd, J. The sound of spiritual care: music interventions in a palliative care setting. Journal of Pastoral Care & Counseling 2011; 65(1), 1-10.
62. Hansen BW, Erlandsson LK, Leufstadius C. A concept analysis of creative activities as intervention in occupational therapy. Scandinavian journal of occupational therapy 2020:1-5.
63. La Cour, K., Josephsson, S., Tishelman, C., & Nygård, L. Experiences of engagement in creative activity at a palliative care facility. Palliative & supportive care 2007; *5*(3), 241-

250.Young R, Camic PM, Tischler V. The impact of community-based arts and health interventions on cognition in people with dementia: A systematic literature review. Aging & mental health 2016;20(4):337-51.
64. Ferrell B, Virani R, Jacobs HH, Malloy P, Kelly K. Arts and humanities in palliative nursing education. Journal of Pain and Symptom Management 2010;39(5):941-5.
65. Centeno C, Robinson C, Noguera-Tejedor A, Arantzamendi M, Echarri F, Pereira J. Palliative care and the arts: vehicles to introduce medical students to patient-centred decision-making and the art of caring. BMC medical education 2017; 17(1):1-0.
66. Murrant GM, Rykov M, Amonite D, Loynd M. Creativity and self-care for caregivers. Journal of Palliative Care 2000; 16(2):44-9.
67. Glenister D. Creative spaces in palliative care facilities: Tradition, culture, and experience. American Journal of Hospice and Palliative Medicine® 2012; 29(2):89-92.
68. Salzano AT, Lindemann E, Tronsky LN. The effectiveness of a collaborative art-making task on reducing stress in hospice caregivers. The Arts in Psychotherapy 2013; 40(1):45-52.
69. Burnside LD, Knecht MJ, Hopley EK, Logsdon RG. here: now–Conceptual model of the impact of an experiential arts program on persons with dementia and their care partners. Dementia 2017;16(1):29-45.
70. Robertson JM, McCall V. Facilitating creativity in dementia care: the co-construction of arts-based engagement. Ageing & Society 2020;40(6):1155-74.
71. Cousins E, Tischler V, Garabedian C, Dening T. A taxonomy of arts interventions for people with dementia. The Gerontologist. 2020; 60(1):124-34.
72. Westheimer O, McRae C, Henchcliffe C, Fesharaki A, Glazman S, Ene H, Bodis-Wollner I. Dance for PD: a preliminary investigation of effects on motor function and quality of life among persons with Parkinson's disease (PD). Journal of Neural Transmission. 2015 Sep 1;122(9):1263-70.
73. Bek J, Arakaki AI, Lawrence A, Sullivan M, Ganapathy G, Poliakoff E. Dance and Parkinson's: A review and exploration of the role of cognitive representations of action. Neuroscience & Biobehavioral Reviews 2020; 109:16-28.
74. Brook J, Booth A. May I have this dance: examining a community based dance program for people living with Parkinson's disease. Research in Dance Education 2020;26:1-5.
75. Hadley R, Eastwood-Gray O, Kiddier M, Rose D, Ponzo S. "Dance like nobody's watching": exploring the role of dance-based interventions in perceived well-being and bodily awareness in people with Parkinson's. Frontiers in psychology 2020; 11.
76. Ulman A, Baker N, Thakker J, Agawane H, Solanki S, Tickle-Degnen L. Dance, cognitive outcomes and Parkinson's disease (PD): A scoping review. American Journal of Occupational Therapy 2020;74(4_Supplement_1).
77. Bruera E, Willey J, Cohen M, Palmer JL. Expressive writing in patients receiving palliative care: a feasibility study. Journal of palliative medicine 2008; 11(1):15-9.
78. Mosher CE, Johnson C, Dickler M, Norton L, Massie MJ, DuHamel K. Living with metastatic breast cancer: A qualitative analysis of physical, psychological, and social sequelae. The breast journal 2013; 19(3):285-92.
79. Low CA, Stanton AL, Bower JE, Gyllenhammer L. A randomized controlled trial of emotionally expressive writing for women with metastatic breast cancer. Health psychology 2010; 29(4):460.
80. Miaskowski C, Paul SM, Snowberg K, Abbott M, Borno H, Chang S, Chen LM, Cohen B, Hammer MJ, Kenfield SA, Kober KM. Stress and symptom burden in oncology patients

during the COVID-19 pandemic. Journal of Pain and Symptom Management. 2020 Nov 1;60(5):e25-34.
81. Lancet T. Palliative care and the COVID-19 pandemic. Lancet (London, England). 2020 Apr 11;395(10231):1168.
82. Iob, E., Frank, P., Steptoe, A. and Fancourt, D., 2020. Levels of Severity of Depressive Symptoms Among At-Risk Groups in the UK During the COVID-19 Pandemic. *JAMA network open*, *3*(10), pp.e2026064-e2026064.
83. Mak HW, Fluharty M, Fancourt D. Predictors and impact of arts engagement during the COVID-19 pandemic: analyses of data from 19,384 adults in the COVID-19 Social Study.
84. Philip KE, Lewis A, Jeffery E, Buttery S, Cave P, Cristiano D, Lound A, Taylor K, Man WD, Fancourt D, Polkey MI. Moving singing for lung health online in response to COVID-19: experience from a randomised controlled trial. BMJ open respiratory research. 2020 Nov 1;7(1):e000737.

Tables and Figures Legend